



Arizona Myeloma Network
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AzMN News

Vol. 1, No. 10 ■ Jan/Feb 2007

The Newsletter for People Interested in Multiple Myeloma

Dear Friends,

As many of you have already heard, I fell and broke my hip on January 9th, after having returned from a wonderful family holiday...not a great way to start the New Year! I had surgery and have pins in my hip and am hobbling about at a quarter of my usual frenzied pace. I have learned a lot and, I know that I have an even deeper appreciation for everyone who has to deal with medical problems, pain, hospitals, insurance, and disabilities. I feel incredibly grateful to good friends, neighbors, family, all the volunteers and AzMN supporters, and the kindness of strangers, or people I hardly knew, who reached out to me via phone and email.

And, thanks to my devoted volunteer staff/committees, our "LIVING WITH MYELOMA CONFERENCE" is right on course. Lyman Smith, AzMN volunteer and Administrator, when he visited me, brought all the conference materials for me to edit and approve. But, more important, I have been surrounded by love and kindness, which we know, is as important as medicine and the good workmanship of my surgeon.

I am thrilled with the early response to our Conference, and the support we have received from Kendra Sabol, the Department of Health Services' Director of the Arizona Comprehensive Cancer Control Program. Our Partnership is a first for Myeloma in Arizona. And, the generous contributions of Millennium, Celgene, The Binding Site, and others, will help us to have a successful, well organized event.

We plan to have other meetings, conferences and programs throughout the State over the next year and look forward to collaborating with other cancer resources on behalf of our myeloma patients.

I hope you will register soon for our March 31st "LIVING WITH MYELOMA CONFERENCE" ...bring friends and family, and if you can't attend, check out our website for other ways that you can help to support AzMN. And, don't forget to put September 21st on your calendar for our 3rd Annual Myeloma Charity Golf Tournament and Dinner.

Fondly, Barbara

SPECIAL INVITATION "LIVING WITH MYELOMA CONFERENCE"

Arizona Myeloma Network (AzMN) in partnership with the AZ Department of Health Services invites you to learn more about "LIVING WITH MYELOMA." Find out the latest in myeloma treatments, current developments; integrative approaches to cancer treatments, and latest research from the leaders in cancer and myeloma research.

**Sat. March 31, 2007,
8:00AM - 4:30PM
InnSuites at Tucson City Center
475 N. Granada Avenue
Tucson, AZ
Tel. 520-622-3000**

Conference features: Rafael Fonseca, MD and Leif Bergsagel, MD of the Mayo Clinic, Scottsdale; John Carpten, Ph.D. of Translational Genomics Research Institute, Phoenix; Michael P. Carroll, MD of Arizona Cancer Center, Tucson; Mark D. Gilbert, MD, F.R.C.P of U of A University Medical Center, Paul Abramson, MD of U of A, Program in Integrative Medicine, and Stacy Watts, National Patient and Survivor Advocacy Spokeswoman.

**For more information or to RSVP,
Please email:
azmyelomanetwork@cox.net
or call: 623.388.6837**

at **www.azmyelomanetwork.org**

**Southwest American Indian
Collaborative Network - 2007 Spiritual
Care Conference**

**Join the Celebration and Ceremonies
for Life's Transitions: Implications for
Cancer Care with American Indians
March 7 and 8, 2007
at the Heard Museum in Phoenix**

**For more information or to RSVP:
Call: 602.258.4822
Email: crystal.thomas@itcaonline.com
www.itcaonline.com**

**One Voice Against Cancer
By: Barbara Kavanagh**



(L-R) Alan Roth, Brenda Gregory, Eileen Roth, Jack Kavanagh, Jennifer Lenz, and Barbara Kavanagh

One Voice Against Cancer is a coalition of healthcare and cancer-related organizations that unite for one day at the Arizona State Capitol to speak with a unified voice on cancer issues facing Arizona, honor cancer survivors, increase awareness of cancer prevention and early detection, and treatment of cancer. AzMN was honored to be part of this important day which was held on Tuesday, February 6th at the State Capitol.

We were fortunate to have Eileen and Alan Roth represent myeloma survivors at the legislative breakfast. Later, Eileen and Alan joined Jack and me, Lyman Smith, AzMN volunteer and Administrator, and Brenda Gregory, our Phoenix Support Group leader, at our table on the lawn outside the Capitol. We handed out information, greeted legislators and visitors, and had an opportunity to educate people about myeloma.

It was the first time I had been anywhere other than the hospital, the doctor's office, or my house in over a month. And, though it was a challenge getting the wheelchair in and out of the car and over the grass, it was wonderful to be with other cancer groups, including the Leukemia Lymphoma Society, American Cancer Society, and The Wellness Community.

**SAVE THE DATE!
SIGN UP EARLY!
Sept. 21, 2007 - 3rd Annual AzMN
Charity Golf Tournament
at Orange Tree Golf Resort
For more information or to RSVP:
Call: 623.388.6837, Email:
azmyelomanetwork@cox.net**

Janice Mindrup's Myeloma Journey... By: Janice Mindrup



I was diagnosed during a routine wellness appointment with my Primary Care Physician, on November 16, 2005...she noticed "...something different..." about me. She asked the typical questions, "How have you been feeling. . . How are things at home? . . . How is work?" I explained that I was very busy at work, long hours, coming home tired, had trouble walking up the stairs to my bedroom. I felt a 'thing' in my lower back; I was achy and I felt like I was carrying a 'heavy load'. I needed to sleep 9-10 hours just to function, when normally I did fine with 7-8 hours of sleep. Any time not at work, I spent sleeping. I noticed the 'thing' in my back for the first time two months before while on a weekend trip to Las Vegas.

She suggested a round of blood tests. . .possibly I could stop by a lab on my way back to work. . .she would call with the results. That evening, she called my home saying. . . 'something is strange.' She suggested repeating the blood work at another lab the next day. I stopped by the second lab on my way to work the next morning. She called my partner, Charlie, and asked if we could both come to her office before the end of the day. Something in the blood results remained 'strange'. She's not an expert about blood, so she suggested a colleague would be able to look at the results.

The next afternoon, Wednesday, November 17, 2005, Charlie and I drove to the Virginia Piper center and met Dr. Maqbool Halepota for the first time. I'll never forget the feeling in my stomach when I read on the door - 'Hematology and Oncology'. I'll also never forget how hard Charlie squeezed my hand while Dr. Halepota was saying the words. . . "multiple myeloma. . .cancer. . .incurable. . .x rays. . .MRI. . .termites. . .plasma cells. . .Swiss cheese. . .chemotherapy. . .keep a positive outlook." After that meeting and after many hours of research on the internet, I wondered several times why all the bones in my hand had not broken because of Charlie's hard squeeze.

The morning after Thanksgiving Day (November 26, 2005) I was admitted to the Scottsdale Shea Hospital for a six-day stay and my first round of chemotherapy. How did I feel? Shock. . .horror. . .scared. . .mis-belief that such a thing could happen to me. Charlie and Debbie were (and continue to be) my caregivers that 'do the work'. They schedule my doctor appointments, since I no longer drive, one of them or both of them go with me to each of these appointments. While we are at the appointments, they are the ones who make certain the paper with our questions and concerns make it to all appointments to be asked. Charlie and Debbie handle all household duties (errands, grocery, repairs, maintenance, housecleaning duties, and cooking). My son, Tim, his former wife, Julie, and my VERY BEST friend in the whole wide world, Peggy, are my 'Disney caregivers'. They don't live with me, but they are the part of my life that allows me to do the 'fun things'.

I endured four rounds of chemo. The first was in the hospital, the remainder were in Dr. Halepota's office (December 2005, January and February 2006). In March I was hospitalized (with a breathing tube down my throat) for fourteen days with Valley Fever. What a terrible ordeal! Before that event, Dr. Halepota had begun communication with the Mayo Hospital's Dr. James Slack and the transplant coordinator, Chris Ehlenbeck. It was decided by all that it would take me a few months to recover from the March ordeal before the autologous transplant was scheduled. Regular visits to the Mayo to meet the team, more blood work and answering all our questions and concerns began in early June. I was admitted to the Mayo on Monday, June 26. Day plus 1 (transplant terms) was June 29.

The first 65 days were terrible; sleeping 20 - 23 hours a day, not being able or wanting to eat or to think about it, not being able to find anything I wanted or could drink, feeling I had the worst possible kind of flu known to man, being confined to my home, worrying my family, feeling so lonely but yet not really caring about anything except maybe the possibility that I could die and get it over with! On the morning of the 66th day, I woke up feeling as though a heavy wool blanket had been taken off my body. I felt great and, I asked for a scrambled egg with sweet/sour sauce! That was September 2.

After my recovery from the transplant, I met with Dr. David Kasper, to arrange a

kypophlasty procedure to relieve the pressure on my spine. I entered the Mayo Hospital on Thursday, November 2nd and Dr. David Kasper, began the one and one-half hour kypophlasty procedure. Immediately after waking in recovery, I could tell something was so much better in my lower back. WOW!!! What relief I felt!! I had been told to expect to spend one night in the hospital for observation. I returned home on Friday morning. I can now walk, climb stairs, bend over, stand, sit in any kind of chair, and lay down on my bed, toss, turn, and thrash about in my bed. At the present time, I visit the infusion center at Virginia Piper once a month for what we call "big blood." On a daily basis I take: a multi-vitamin, Folic acid, Coumadin/Warfarin (I had blood clots during the Valley Fever), Potassium, and a Calcium Supplement. Once a month I receive Zome.

The Phoenix Support Group has been vital to my recovery and succeeding in this fight. My doctor is wonderful, my family and friends are wonderful, the internet is wonderful, pamphlets picked up in libraries are wonderful, but there is something unique about hearing how other people are 'doing it'. My support group at The Wellness Center has taught me the questions to ask, the symptoms that should not be over-looked and need to be mentioned to my doctor, medications that have worked/not worked for others, clinical trials, what our government is doing/or not doing to fight this disease, to keep my sense of humor, to 'be kind to myself', and to accept that this has happened and they are all there just a phone call away.

General Information

Articles from our readers are welcome and should focus on information directed towards Multiple Myeloma. Articles are due the first week of each month. Please send inquiries to:

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AzMNewsletter and advertisement details and costs are available by contacting us at the above address.

